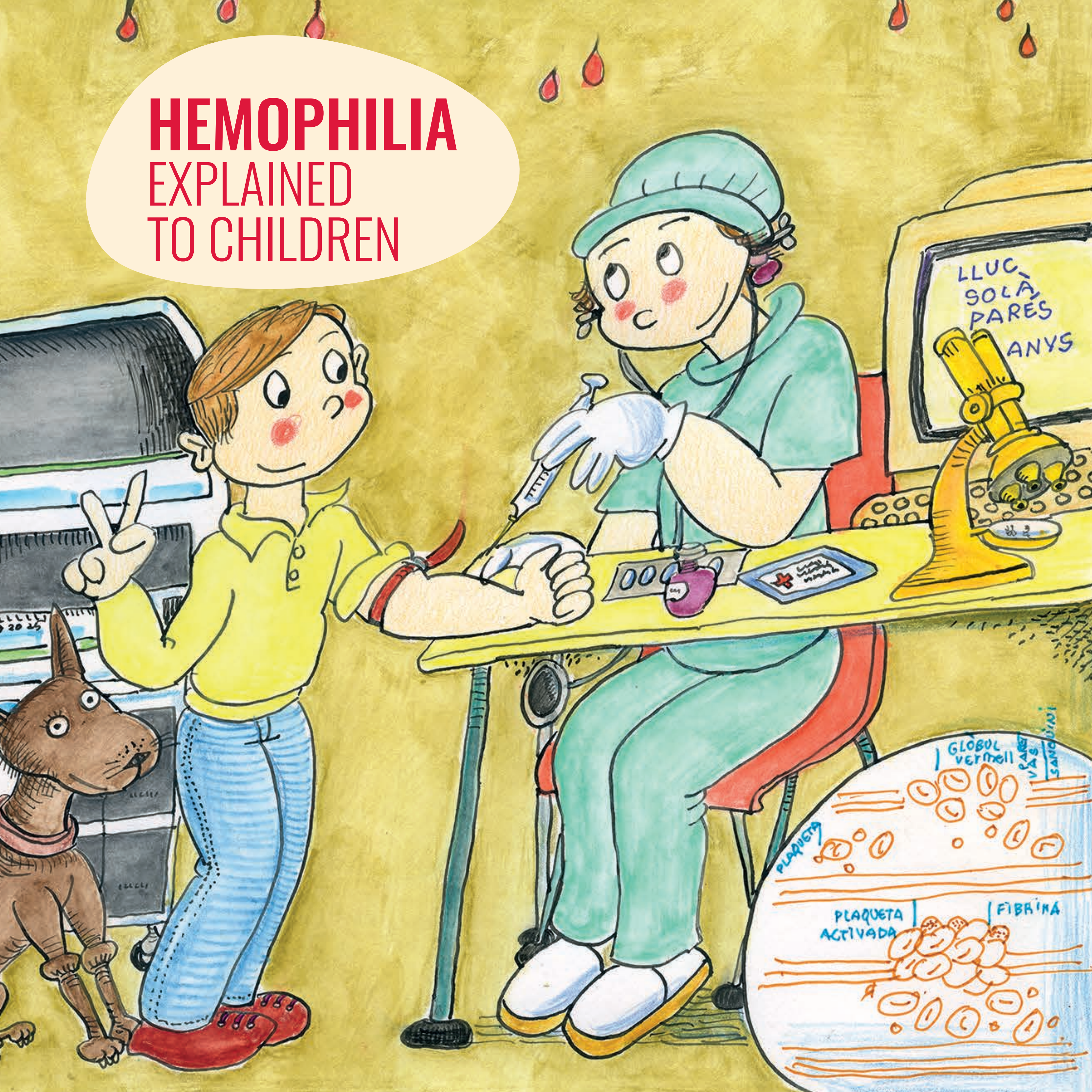
HEMOPHILIA
EXPLAINED
TO CHILDREN



ACH Associació
Catalana de
l'Hemofília

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HEMOPHILIA
EXPLAINED TO CHILDREN

We are unique, we are special.

With this story, we want to help **children with hemophilia and girls who are carriers of hemophilia** to understand their condition and how it is passed on through genetics. Hemophilia is one characteristic, but there are so many other things that make us who we are: **unique and special.**

Hello! My name is **Roc**, and I'm the guard dog at the most beautiful school in my city.

I have the best job in the world: playing with children all day long!

Most kids greet me with cuddles and smiles, but some never come near me because they're a bit scared. I don't understand why...

I don't bite, I don't bark, I don't make angry faces, and I'm always happy.

I just want to play and have fun!

Today I'm very excited because it's Saint Eulàlia's Day, and we're having a party at school.

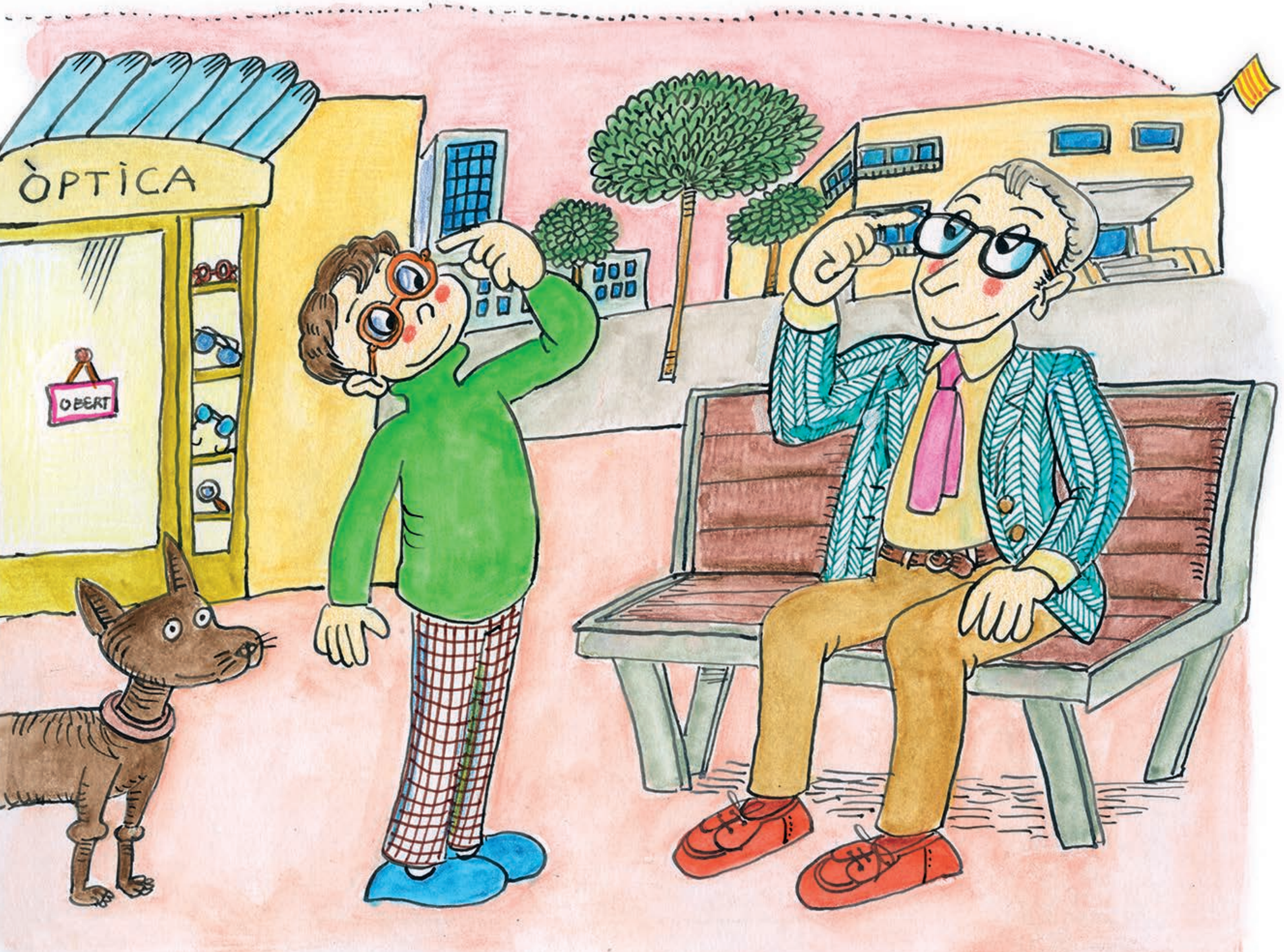
The primary students are doing a **scavenger hunt about genetics.**

I'm a bit lost because I don't know what genetics is.

Do you know?

Nil has solved **the first challenge.** He guessed that **glasses** are what people need to see well, both up close and far away.

He has worn them since he was little, just like his father. But not everyone needs glasses.



In **the second round**, all the children went under the biggest tree in the playground, where many different fruits were hanging. They had **to find a fruit** that matched the color of the least common hair.

Maria solved it right away. Do you know why? Because she has **orange hair** and her face and body are covered in tiny freckles.

The first day I saw her, I was surprised because I had never seen a girl with that hair color. But then I noticed that her whole family is redheaded.

On the basketball court, they had drawn a **giant map of the world.** The challenge was to color all the countries where lions live.

Keita immediately colored the **African continent.** His father was born in Kenya and always tells him about the adventures he had as a child in his village with the wild animals.

With these three challenges, we learned that **genetics** makes each of us inherit **some trait from our father and others from our mother.**

Some things can be seen easily, like eye color, freckles, skin tone, etc.

Now I understand why my ears are pointy: they're just like my mother's!

Other characteristics aren't visible.

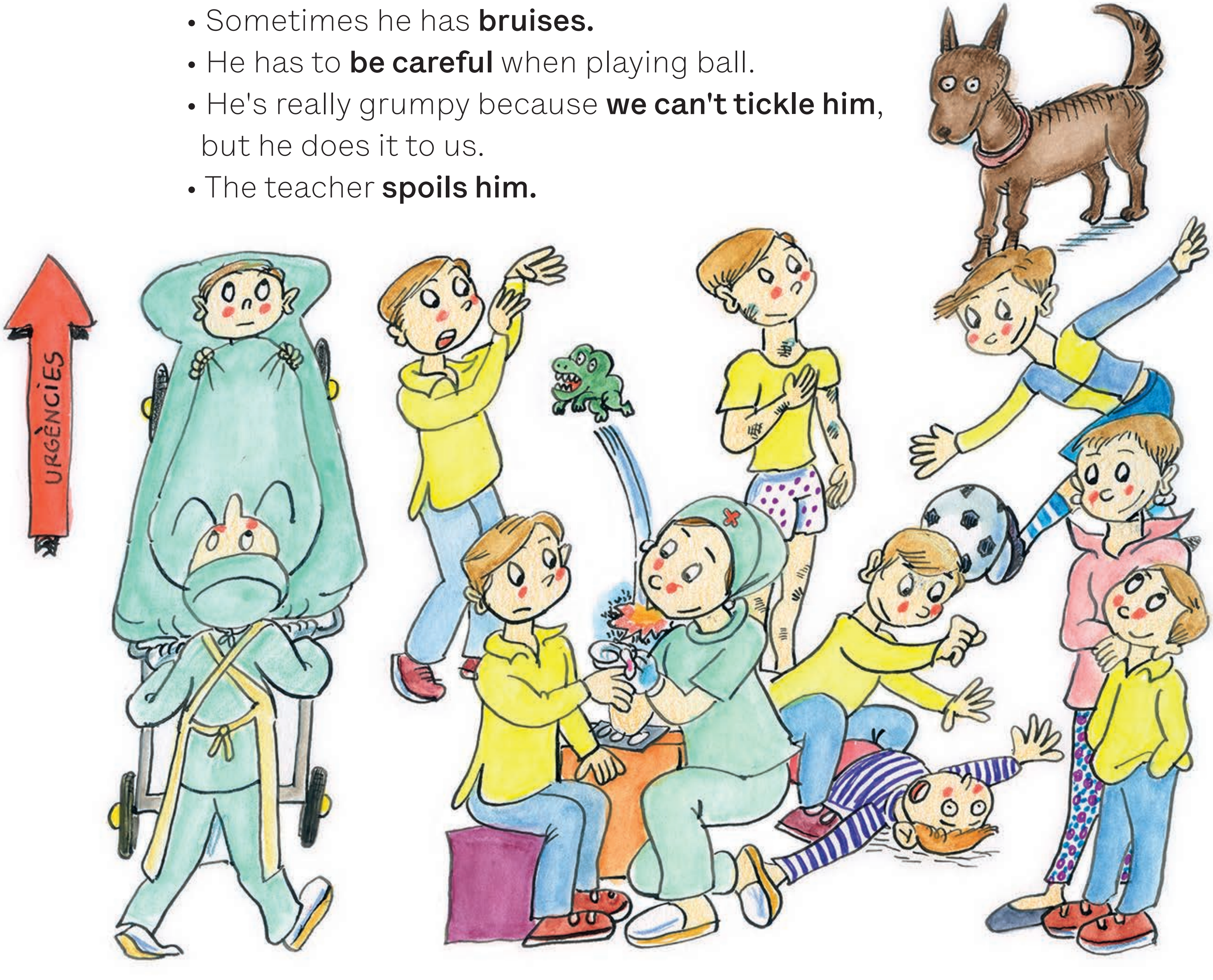
Lluc, who **has hemophilia**, knows this very well.

The final challenge of the scavenger hunt is to investigate **what happens** to Lluc.

Teresa, the science teacher, asks all the boys and girls what they know about hemophilia.

Some of the ideas they share are:

- It involves going to **the hospital.**
- He can't **get hurt.**
- He gets **injections** and they put on some really fun band-aids.
- Sometimes he has **bruises.**
- He has to **be careful** when playing ball.
- He's really grumpy because **we can't tickle him**, but he does it to us.
- The teacher **spoils him.**



Vintu says she saw on the internet that hemophilia has to do with blood.

She's right: **hemophilia is related to blood.**

Blood contains different elements, and people with hemophilia don't produce one of these components, or they produce very little of it: **the clotting factor.**

For this reason, **children with hemophilia**:

- Must go to the hospital more often, to the **Hemophilia Treatment Center**, for check-ups.
- Need to get a **treatment injection.** This must always be done at home or at the hospital.
- Thanks to this injection, **they can do most things**, just like all other children.
- If they get a **strong hit** or fall, it's important to **notify** their caregivers so they can go to the Hemophilia Treatment Center.
- Also, **applying ice** right away is important.

Now
I understand
why **Lluc**
sometimes
arrives late.

He probably
had a **check-up
at the
Hemophilia
Treatment
Center** before
coming to
school.

But I can assure
you he jumps
and hops like a
kangaroo.

I would never
have guessed
he had
hemophilia.

If hemophilia is genetic, I wonder why his **sister Carlota**, who talks non-stop, doesn't go to the hospital.

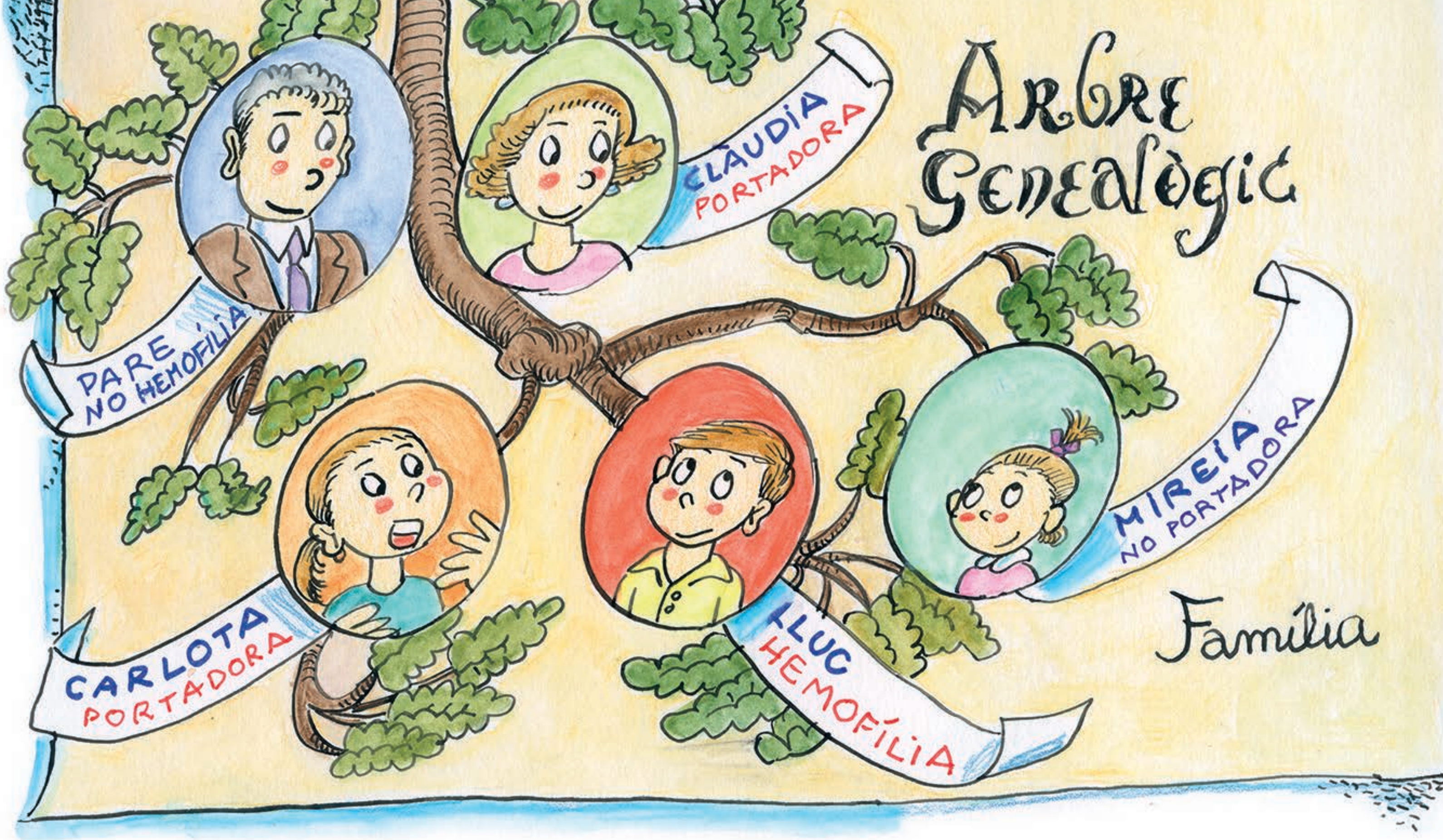
Could it be that **only boys can have hemophilia?**

Carlota explains that she is a **carrier of hemophilia.**

At the hospital, they **checked whether she produces clotting factor and in what quantity.**

Some girls who are carriers make enough, and others produce very little.

She doesn't go to the hospital as often as her brother because **she produces the factor she needs.**



Genetics explains why **Carlota** is a **carrier.** As we've learned, everyone inherits certain traits from their father and their mother.

In her family, her **mother**, **Claudia**, is a **carrier**, and that has caused her brother, **Lluc**, to have **hemophilia** and her to be a carrier, like her mother.

They have another sister, **Mireia**, who **is not a carrier.**

Genetics works like that: **we are all different because we inherit different characteristics.**

LLUC'S FAMILY (HEMOPHILIA)

When Lluc grows up and becomes a father, all of his **daughters will be carriers**, but **none of his sons will have hemophilia.** That's how genetics works: every person is unique because we inherit different combinations!

CARLOTA'S FAMILY (CARRIER)

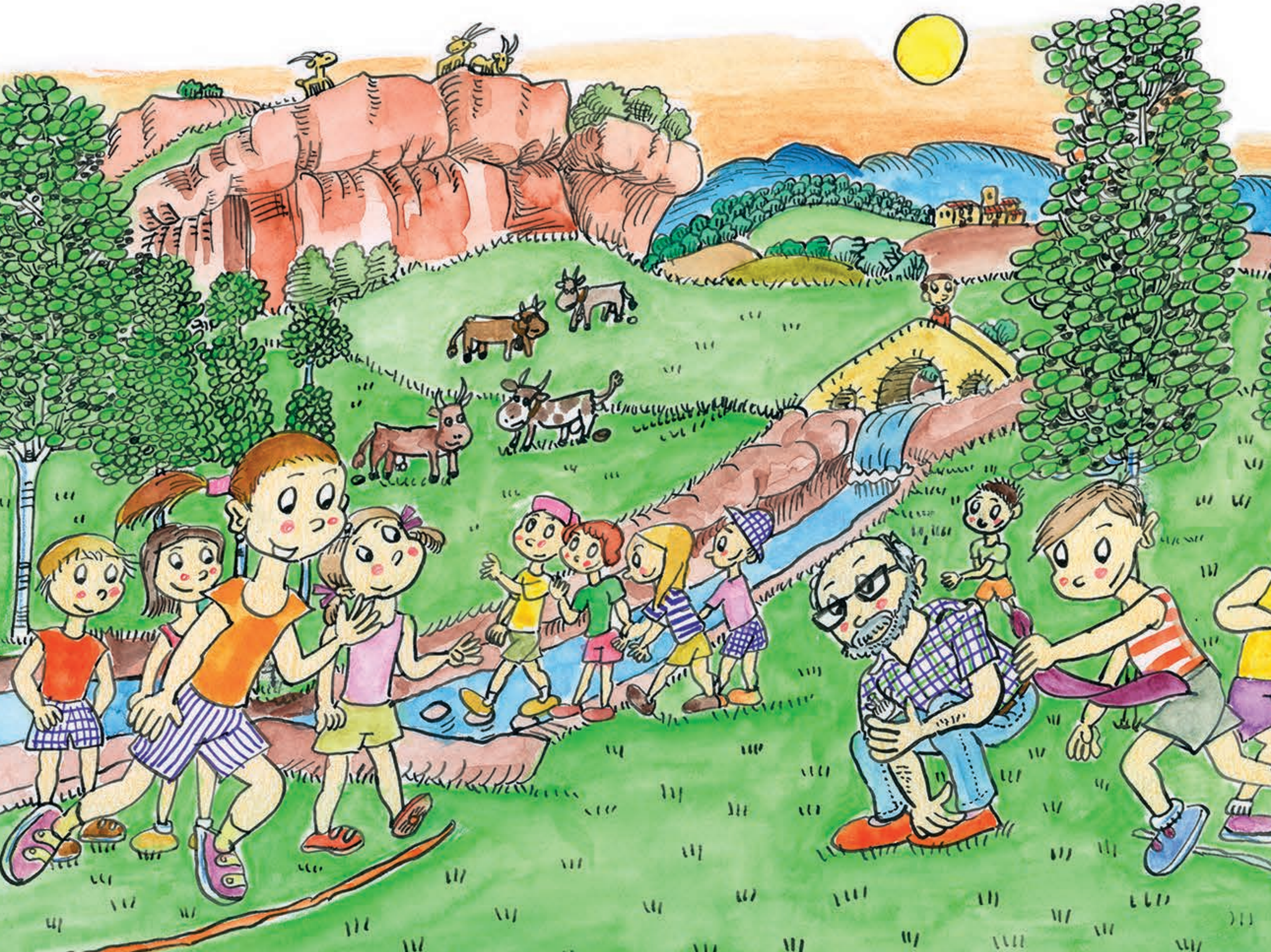
On the other hand, when **Carlota** becomes **a mother**, **some of her sons** may have **hemophilia**, and **some of her daughters** may be **carriers.**

But she may also **have sons without hemophilia** and **daughters who are not carriers.**

Once again, genetics will make each child different.

I remember that when school starts in September, **Carlota** and **Lluc** always share the adventures they had at the summer camps organized by the **Catalan Hemophilia Association.**

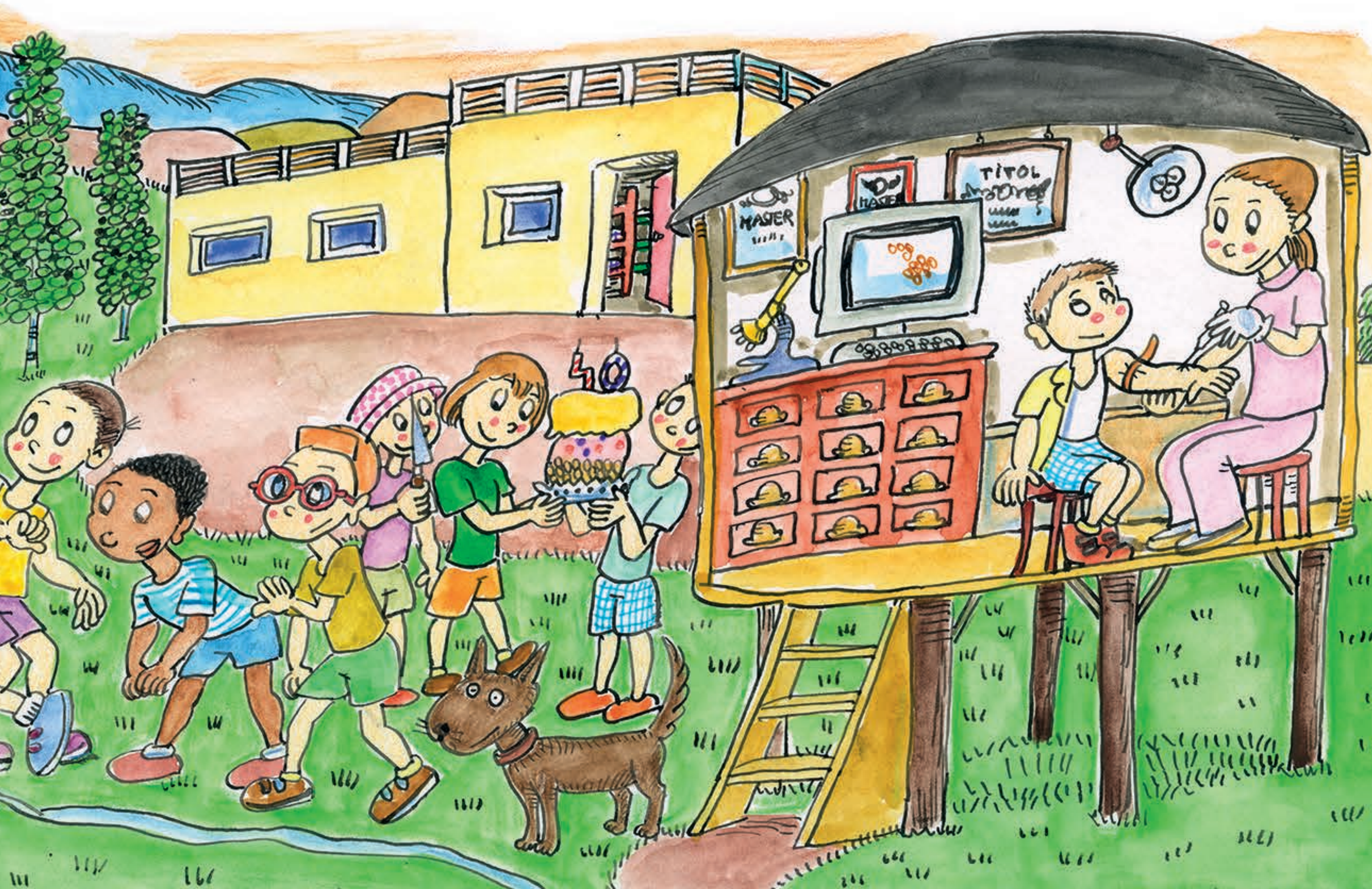
This summer, some of **their school friends** will also go there too!

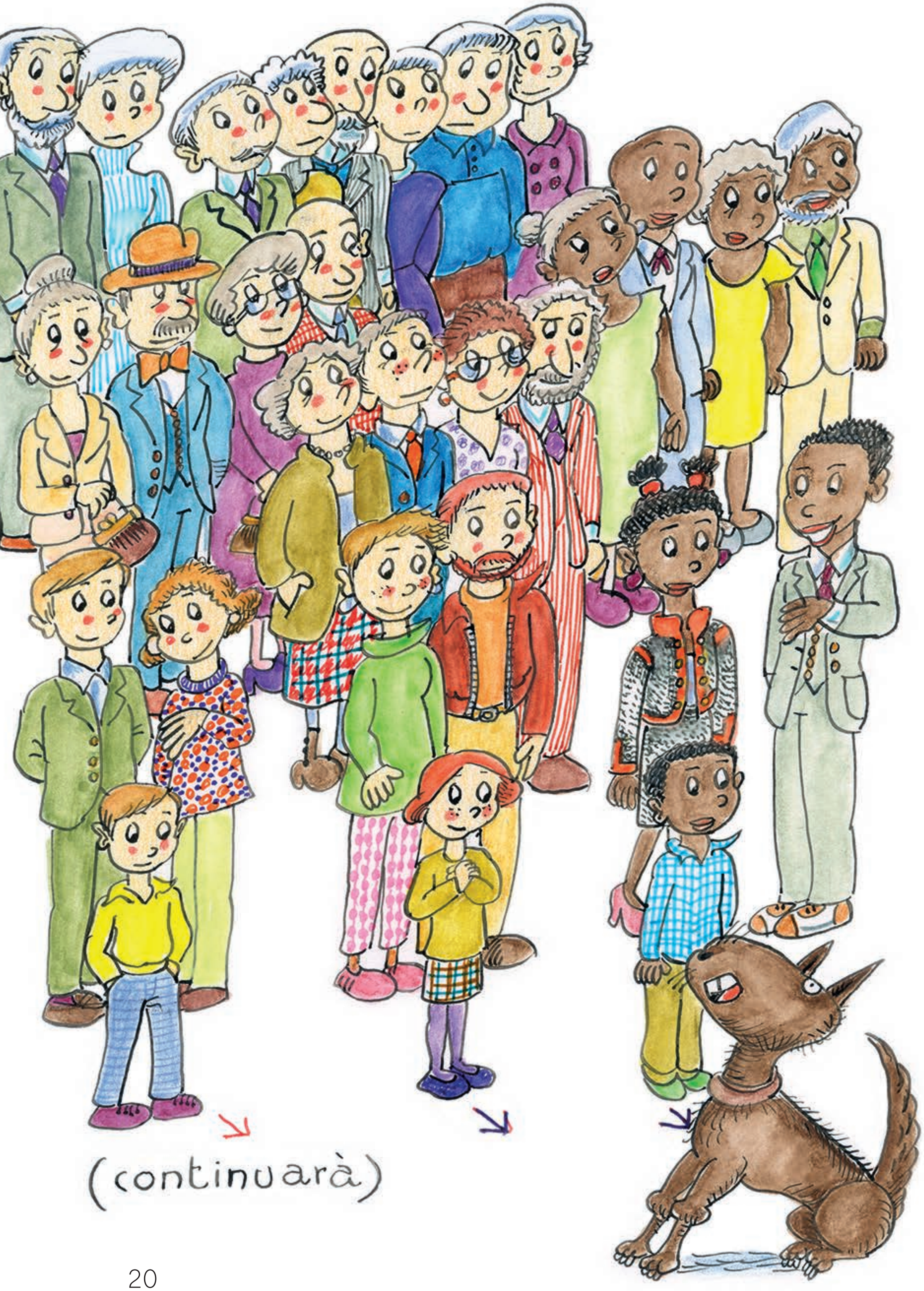


Children with hemophilia and girls who are carriers can visit the Hemophilia Treatment Center or the Association whenever they need to.

At the **hospital**, they go for check-ups, receive treatment, blood tests, or to learn more about their hemophilia.

At the **Association**, they meet other boys and girls like them, talk about their experiences, have fun together at the summer camps, and sometimes even go skiing on some winter weekends.





I've already told you many things about some of the boys and girls at school.

Have you noticed that **they're all different?**

Do you know why?

Because of genetics.

Genetics lays the foundation for who we are.

It makes us unique and special.

But there are **many other things** in life: the family we have, the education we receive, the friends we choose, and the people who help us when we need it.

All this makes us who we are, and there will be **no one in the world exactly like you or me.**

And the most important thing: we **all want to be happy and have fun!** Like today, during the scavenger hunt.

Snip, snap, snout, this tale's told out.

ACTIVITIES TO THINK AND PLAY AS A FAMILY

As Roc says, many traits are determined by genetics.

Now it's your turn to keep exploring:

- What do you think are the traits you've **inherited from your father?**
- Which ones **from your mother?**
- Which characteristics **are visible?**
- Which ones **cannot be seen?**
- What makes you **special and unique?**
- What makes **you happy or feel better?**

As Roc says, there are many other things in our lives besides genetics.

We suggest some games to have fun with the family.

The Wishes Game

Each family member writes a wish on a piece of paper.

All the papers go into a container.

One paper is chosen and read aloud.

The rest of the family **uses imagination to make that wish come true.**

You can choose one day of the week to pick a paper, and during the week you think about how to make it happen, until it's time to play.

Each week, only one paper is drawn from the container, so each time it will be a different family member's turn to have their wish fulfilled.

However, if you have the time, you can also play them all at once in a single day. You can make as many variations as you want!

The point is for **each family member to be the star for a day and see their wish come true.**

Game: Summer is magical

Each family member writes **something fun to do in the summer** holidays that **doesn’t cost extra money.**

One day during the summer, we do whatever each family member has chosen.

This way, for one day during the summer, **one of the family members will be the star** and their suggested activity will be carried out so we can all have a great time.

We want to express special thanks to **Pilarin Bayés** who illustrated this story generously with her beautiful drawings.

We also want to acknowledge the work of the **Interdisciplinary Working Group for supporting women with hemophilia and their families**, which has driven the creation of this story to provide support and visibility to this reality.

And, very especially, we thank the **people who have written and reviewed it** with sensitivity, dedication, and affection, making it possible for this story to come to life.

Pilarin Bayés is a much-loved illustrator born in Vic. She has loved drawing since she was a little girl. With her unique style and **her characters with rosy cheeks**, many generations of boys and girls have discovered the pleasure of **reading, writing, drawing, and dreaming.**

Her joy, charisma, and creativity have made her a major figure in illustration in Catalonia.

She has published more than a thousand stories, which have been translated into many languages, and has **received numerous awards and honors**, such as the Cross of Saint Jordi.

The interdisciplinary working group was created by the Advisory Council of the Catalan Hemophilia Foundation, and is composed of professionals from various disciplines such as **hematology, nursing, psychology, education, genetics, and gynecology**, from:

- The Catalan Hemophilia **Association** and the Catalan Private Hemophilia **Foundation.**
- **The Integrated Hemophilia Unit** of Sant Joan de Déu Hospital – Sant Pau Health Campus, CSUR Coagulopathies, and members of Eurobloodnet.
- The **Genetic and Molecular Medicine Service** of Sant Joan de Déu Hospital in Barcelona, SJD Pediatric Institute for Rare Diseases.

ACH Associació Catalana de l'Hemofília

FPCH Fundació Privada Catalana de l'Hemofília

SJD Sant Joan de Déu Barcelona · Hospital

SANT PAU Campus Salut Barcelona

Hospital de la Santa Creu i Sant Pau

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